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ABSTRACT

Genetic disease and birth defects pose a unique set of concerns for affected individuals and their families. The need of these individuals for pastoral care--guidance for difficult decisions, bereavement counseling, and support--has opened a new area of ministry for pastors and pastoral counselors of all faiths. This ministry occupies the intersection of the disciplines of pastoral care, bioethics, and genetic counseling. This bibliography is intended both to introduce pastors, pastoral care workers, and educators to this unique dimension of health care and to assist them in extending their knowledge of the field. With the exception of a few classic articles, only material from the last ten years is included in this edition. The bibliographies are classified into four chapters: (1) "New Frontiers in Biology: Ethical, Legal, and Theological Concerns"; (2) "Clergy Involvement in Genetic Counseling"; (3) "The Religious Community and Persons With Disability"; and (4) "Support for Families." (YP)

RESOURCES FOR CLERGY IN HUMAN GENETIC PROBLEMS

A Selected Bibliography

1988 Edition

SE 051 009

NCEMCH
National Center for Education in Maternal and Child Health

March of Dimes

Resources for Clergy in Human Genetic Problems

A Selected Bibliography

Second Edition
May 1988

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The National Center for Education in Maternal and Child Health (NCEMCH) provides information services, educational materials, and technical assistance to organizations, agencies, and individuals with maternal and child health interests. The Center was established in 1982 at Georgetown University, within the Department of Obstetrics and Gynecology. NCEMCH is primarily funded by the U.S. Department of Health and Human Services, through its Bureau of Maternal and Child Health and Resources Development.

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Contents

Preface

Genetic disease and birth defects pose a unique set of concerns for affected individuals and their families. The need of these individuals for pastoral care—guidance for difficult decisions, bereavement counseling, and support —has opened a new area of ministry for pastors and pastoral counselors of all faiths. This ministry occupies the intersection of the disciplines of pastoral care, bioethics, and genetic counseling. The demand for clergy familiar with genetics who can provide this new ministry has been dramatically stimulated by the rapid expansion in the diagnosis and treatment of birth defects and genetic disorders.

However, an immense and growing body of literature exists in the various disciplines that comprise this new ministry. Keeping abreast of this literature is a difficult job for the already busy pastor or pastoral care worker. Moreover, many of the journals and books are not readily available, except at major medical centers or universities. This bibliography is intended both to introduce pastors, pastoral care workers, and educators to this unique dimension of health care and to assist them in extending their knowledge of the field.

The Division of Genetics at Georgetown University School of Medicine has long had an interest in familiarizing clergy with genetics and in preparing them for more adequate ministry in this field. The first edition of this bibliography evolved from the course, "Clergy Education in Human Genetics Problems," which was sponsored by the March of Dimes Birth Defects Foundation and presented by the Division of Genetics during the summer of 1984. The bibliography has supplemented subsequent sessions of this course which have been held yearly since 1984.

The response to the first edition was very gratifying, indicating that this bibliography does indeed meet an educational need. The publication of many new articles and books in the four years since the first edition has necessitated a new edition. Over two hundred new references have been included. Since this publication is for practicing clergy rather than scholars, citations more than ten years old were deleted, with a very few exceptions for classic books. No bibliography is ever complete, and important sources can be overlooked. Therefore I welcome suggestions from readers for material that should be included in the next edition.

Frank D. Seydel, Ph.D., M.Div.

Acknowledgements

I would like to express my deep appreciation to the Bureau of Maternal and Child Health and the March of Dimes Birth Defects Foundation, whose financial support has made this bibliography possible from its inception through this second edition. I would also like to thank Robert C. Baumiller, Ph.D., S.J., Chief of the Division of Genetics at Georgetown University Medical Center, who conceived the Program for Clergy Education in Genetics, from which this project arose, and who has energetically promoted this project. In addition, the staff at the National Center for Education in Maternal and Child Health deserve thanks for their extensive editorial and literature search efforts.

F.D.S.

How To Use This Guide

All items in this bibliography have been annotated. Citations follow the American Psychological Association style manual. The bibliography has been organized topically. Each topic has been further divided into two sections: the first section contains books and periodical articles arranged alphabetically by author; the second section lists journals and periodicals that frequently contain articles on the topic. Many works, especially the proceedings of meetings, touch on several of the topics listed. However, each item is cited only once, under the topic which seems most appropriate.

The bibliography is intended to acquaint clergy and pastoral care workers with current information. Thus, with the exception of a very few classic articles, only material from the last ten years is included in this edition. All items are currently in print. Journals and books should be available from major libraries by interlibrary loan. Emphasis has been placed on the role of religion in general and the role of clergy in particular in dealing with concerns in human genetics. Additional material on such topics as bereavement, bioethics, genetics, pastoral care, and social work can be obtained by consulting references in those fields.

Chapter 1

New Frontiers In Biology: Ethical, Legal, and Theological Concerns

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General Bioethics

Books and Articles

Craig, R. P., Middleton, C. L., & O'Connell, L. J. (1986). *Ethics committees: A practical approach.* St. Louis: Catholic Health Association of the United States.

The why, what, and who of ethics committees, covering membership, structure, religious perspective, history of the *Ethical and Religious Directives for Catholic Health Facilities*, corporate decision making, committee meetings, and evaluation. Available from Catholic Health Association of the United States, 4455 Woodson Road, St. Louis, MO 63134-0889.

Doherty, D. J. (1985). Contemporary medical ethics: Would Hippocrates approve—or even understand? *Medical Ethics*, 77(3), 212-216.

An introductory survey of current medical ethics topics, emphasizing their complexity.

Gervais, K. G. (1987). *Redefining death.* New Haven, CT: Yale University Press.

A criticism of the Uniform Declaration of Death Act with a survey of recent proposals for definitions of death, and an alternative definition of death as the persistent cessation of consciousness.

Harron, F., Burside, M., & Beauchamp, T. (1983). *Health and human values: A guide to making your own decision.* New Haven, CT: Yale University Press.

Basic primer in medical ethics. The chapters on prenatal diagnosis and applied genetics are especially pertinent.

Kass, L. R. (1985). *Toward a more natural science: Biology and human affairs.* New York: Free Press/Macmillan.

A collection of essays on the philosophy of nature. Contains five essays on reproductive technology (some originally published in the early 1970's) and four on medical ethics.

Reich, W. T. (Ed.). (1978). *Encyclopedia of bioethics.* New York: Free Press.

A comprehensive reference, with listings from abortion to zygote.

Ross, J. W., Bayley, C., Michel, V., & Pugh, D. (1986). *Handbook for hospital ethics committees: Practical suggestions for ethics committee members to plan, develop, and evaluate their roles and responsibilities.* Chicago: American Hospital Publishing.

Provides a history and overview of bioethics; discusses the resolving of bioethics dilemmas; surveys the legal system, issues of privacy, confidentiality, and liability. Contains seven appendices including,"Religion and Health Care Ethics." Includes a multimedia bibliography and an index. Available from American Hospital Association, 211 East Chicago Avenue, Chicago, Illinois 60611.

Shannon, T. A. (1987). *An introduction to bioethics.* Mahwah, NJ: Paulist.

Offers an overview of the ethical questions created by biotechnology. Includes a chapter on genetic engineering. Each section contains questions for discussion and resources for further study.

Varga, A. C. (1984). *The main issues in bioethics.* Ramsey, NJ: Paulist.

Surveys and discusses the issues of eugenics, reproductive technologies, and genetic engineering. Provides an overview of the scientific background and data for each issue discussed.

Walters, L., & Kahn, T. J. (Eds.). (1984). *Bibliography of bioethics (Vol. 10).* Washington, DC: Kennedy Institute of Bioethics.

A yearly compendium of citations in the field of bioethics. The bibliography is produced at the Kennedy Institute of Ethics, Georgetown University. Contents also available in an online database, BIOETHICSLINE, in the National Library of Medicine's MEDLARS network. Vols. 1-9 are available from Gale Research Co., Book Tower, Detroit, MI 48226.

Journals and Periodicals

Bioethics Quarterly. Human Science Press, 72 Fifth Avenue, New York, NY 10011.

Multidisciplinary consideration of bioethical dilemmas, including those of concern in the practice of genetics. Published quarterly.

The Hastings Center Report. 255 Elm Road, Pleasantville, NY 10510.

An interdisciplinary, bioethics journal devoted primarily, but not exclusively, to secular bioethics. Published monthly.

Journal of Medical Ethics. Tavistock House East, Tavistock Square, London, England WC1 H9JR.

This journal includes papers on medical ethics, analyzes ethical concepts and theories, and features case conferences and comment on clinical practice. Published quarterly.

The Journal of Medicine and Philosophy. D. Reidel Publishing Co., P.O. Box 17, 3300 AA, Dordrecht, Holland.

Deals with the philosophical foundation for the nature of medical practice; occasionally has articles on genetic health care. Published quarterly.

The Journal of Science and Religion. The Joint Publication Board of Zygon, The Council on the Study of Religion, Wilfred Laurier University, Waterloo, Ontario, Canada N2L 3C5.

This journal gives a broad, philosophical view of the interaction of science and religion. Published quarterly.

Kennedy Institute Newsletter. Kennedy Institute of Ethics, Georgetown University, Washington, DC 20057.

Provides short essays and an annotated bibliography of recent publications in bioethics. Published bimonthly.

New Titles in Bioethics. Kennedy Institute of Ethics, Georgetown University, Washington, DC 20057.

A listing of the Kennedy Institute's bioethics bibliographies. Published annually.

Perspectives in Biology and Medicine. University of Chicago Press, Journals Division, P.O. Box 37005, Chicago, IL 60637.

Reflective articles on general ethical and philosophical aspects of biology and medical issues. Published quarterly.

Scope Note. National Reference Center for Bioethics Literature, Kennedy Institute of Ethics, Georgetown University, Washington, DC 20057.

Each issue provides an annotated bibliography and review essay for a single bioethics topic. Published bimonthly.

Medical Ethics and Religious Tradition

Books and Articles

Ashley, B. M., & O'Rourke, K. D. (1982). *Health care ethics: A theological analysis.* St. Louis: Catholic Health Association of the United States.

A systematic examination of the theological foundation for contemporary health care. Chapters include The Health Seeker, The Healing Profession, Bioethical Decision Making, Difficult Bioethical Decisions, and Pastoral Ministry in Health Care. The book provides a thorough background for the practice of genetic health care from the Roman Catholic point of view. Much of the presentation can be extended to other traditions as well. Available from Catholic Health Association of the United States, 4455 Woodson Road, St. Louis, MO 63134-0889.

Feldman, D. M. (1986). *Health and medicine in the Jewish tradition: L'hayyem—to life.* New York: Crossroad.

The fourth monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different faiths. This volume examines mental and physical health, marriage and procreation, abortion, aging, and right to life from the fundamental Jewish perspective of the Torah.

Franck, I. (1983). Moral dilemmas that are acute within a religious tradition: A Jewish perspective. *Hospital Practice. 18*(7), 192-196.

Considers the Jewish imperative to preserve life in regard to five genetic dilemmas: the risks and benefits of group screening for Tay-Sachs disease, the desire of two mentally retarded persons to marry, medical intervention for affected newborns, the definition of death, and the use of prenatal diagnosis.

Gribetz, D. T. (Ed.). (1984). Medical ethics: The Jewish point of view [Special issue]. *The Mount Sinai Journal of Medicine, 51*(1).

Special 50th year anniversary issue dealing with the range of medical ethics. Topics covered include *in vitro* fertilization, abortion, genetics and amniocentesis, and the treatment of chronically ill infants.

Hauerwas, S. (1986). *Suffering presence: Theological reflections on medicine, the mentally handicapped, and the Church.* South Bend, IN: University of Notre Dame Press.

A three-part discussion. The first covers medicine and the church, professional authority in medicine, and suffering and death. The second addresses suicide, brain death, the ethics of experimentation with human subjects (including children), and *in vitro* fertilization. The third covers ethical issues involved in preventing, and in caring for persons with, mental retardation and other disabilities.

Holifield, E. B. (1986). *Health and medicine in the Methodist tradition: Journey toward wholeness.* New York: Crossroad.

The sixth monograph in a ten-part series dealing with central themes in health and medicine from the perspectives of different faiths. This volume deals with healing, suffering, dying and death, morality, stages of life, sexuality, caring, and well-being from the Methodist focus of the journey towards holiness.

Kissinger, W. S. (Ed.). (1986). Brethren, life and thought [Special issue]. *Brethren Journal, 31*(4).

This issue of the theological quarterly of the Church of the Brethren consists of seven articles on medical genetics and biotechnology.

Lammers, S. E., & Verhey, A. (1987). *On moral medicine: Theological perspectives in medical ethics.* Grand Rapids, MI: William B. Eerdmans.

An anthology of 105 contemporary essays on medical ethics, most from religiously informed perspectives. Chapter topics include: religion and medicine, theology and medical ethics, professional integrity, the sanctity of life, health and healing, death and its dignity, the mastery of nature, patients and their suffering, respect for persons, contraception, reproductive technology, genetic control, abortion, euthanasia, neonatal care, the physician-patient relationship, psychiatric care, research ethics, and distributive justice. Includes work by Karl Barth, Hans Jonas, Leon Kass, C.S. Lewis, Paul Ramsey, Paul Tillich, and Robert Veatch.

Marty, M. E. (1983). *Health and medicine in the Lutheran tradition: Being well.* New York: Crossroad.

The first monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different religious faiths. This volume covers wellness and illness, caring and curing, and passages in life from the perspective of the "world centeredness" of the Lutheran tradition.

Marty, M. E., & Vaux, K. L. (Eds.). (1982). *Health/medicine and the faith traditions: An inquiry into religion and medicine.* Philadelphia: Fortress.

The introductory volume for a ten-part series dealing systematically with core themes in health and medicine from the perspectives of different religious faiths.

McCormick, R. (1984). *Health and medicine in the Catholic tradition: Tradition in transition.* New York: Crossroad.

The third monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different faiths. This volume examines morality, justice, sexuality, and dignity as they relate to health issues from the Roman Catholic perspective of well-being and totality.

McCormick, R. (1983). Moral dilemmas that are acute within a religious tradition. A Catholic perspective. *Hospital Practice 18*(7), 196-198.

McCormick compares the Roman Catholic moral imperative to preserve life with the pastoral need to place the imperative within the content of particular lives.

Rosner, F., & Bleich, J. D. (Eds.). (1979). *Jewish bioethics.* New York: Hebrew.

Touches on several issues of interest in human genetics, including test-tube babies and pregnancy termination. Tay-Sachs disease is presented as a case study for the ethical concerns in screening.

Seydel, F. D. (1983). The biological revolution: Challenge for the church. *Engage/Social Action, II*(10), 10-15.

Discusses the spectrum of theological, ethical, and pastoral issues raised by contemporary biological research.

Seydel, F. D. (1982). Guidelines for genetic change. *The Christian Home, 14*(4), 42-47.

Provides suggestions for resolving conflicts arising from questions about the nature and quality of life and the beginning of individual life.

Smith, D. H. (1986). *Health and medicine in the Anglican tradition: Conscience, community, and compromise.* New York: Crossroad

The fifth monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different religious faiths. This volume deals with mortality, decisions about death, and sexuality and new life from the perspective of the central Anglican theme of communion or sharing.

Vaux, K. L. (1984). *Health and medicine in the Reformed tradition: Promise, providence, and care.* New York: Crossroad.

The second monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different faiths. This volume examines issues surrounding the nature of humanness, such as well-being, suffering, sexuality, healing, and mortality, from the central Reformed perspective of redemption.

Weisbard, A. J. (1979). On the bioethics of Jewish law: The case of Karen Quinlan. *Israel Law Review, 14*(3), 337-368.

Discusses the Jewish legal concepts of *goses* (being in the state of imminent death), *trefah* (being in the state of having a fatal organic disease), and *pikuach nefesh* (the duty to save life), as they apply to the Quinlan case. However, these concepts apply as well to such arenas as the neonatal intensive care unit.

Journals and Periodicals

Journal of Religious Ethics. Notre Dame University Press, Notre Dame, IN 46556.

Deals with broad ethical concerns from the perspective of religious traditions. Occasionally deals with medical ethics. Published biannually.

Medical Genetics and the Law

Book and Articles

Andrews, L. B. (1987). *Medical genetics: A legal frontier.* Chicago: American Bar Foundation.

Provides an overview of the laws that affect clinical and research aspects of medical genetics. Available from the National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, DC 20057.

Holder, A. R. (1985). *Legal issues in pediatrics and adolescent medicine.* New Haven, CT: Yale University Press.

Covers legal issues of fetal research, amniocentesis, genetic counseling, genetic screening, *in vitro* fertilization, artificial insemination, surrogacy, adoption, contraception, sterilization, abortion, human experimentation, and sale or rental of human organs.

Milunsky, A., & Annas, G. J. (Eds.). (1985). *Genetics and the law III.* New York: Plenum.

Proceedings of the Third National Symposium on Genetics and the Law. Contributors explore law and regulation, academic/corporate interfacing, gene mapping and its implications for free choice and privacy, genetic alteration of embryos, AIDS, surrogacy and *in vitro* fertilization, embryo transfer, eugenic sterilization, "infant Doe" regulations, abortion, the extension of child abuse laws to cover fetal abuse, prenatal diagnosis, fetal surgery, Federal Drug Administration supervision of alpha feto-protein test kits, regulation of fetal experimentation, compensation for workplace and environmental genetic hazards, and the influence of commerce in human genetics.

Milunsky, A., & Annas, G. J. (Eds.). (1980). *Genetics and the law II.* New York: Plenum.

From the National Symposium on Genetics and the Law. Extensive updating and supplementing of Volume I. Volume II discusses the legal and ethical issues in government control of science, genetic counseling and screening, eugenics, the control of genetic disease, family law, and the regulation of mutagens and teratogens.

Milunsky A., & Annas, G. J. (Eds.). (1976). *Genetics and the law.* New York: Plenum.

From the National Symposium on Genetics and the Law. Includes discussion of genetic mass screening, human experimentation, eugenics, genetic counseling, the status of the newborn, *in vitro* fertilization, and other related topics.

Nicholson, R. H. (Ed.). (1986). *Medical research with children: Ethics, law, and practice.* New York: Oxford University Press.

A report of the Institute of Medical Ethics working group on the ethics of clinical research investigations on children. Glossary and index are included.

Journals and Periodicals

American Journal of Law and Medicine. American Society of Law and Medicine, 765 Commonwealth Avenue, Boston, MA 02215.

A number of legal-medical articles touch on issues of interest to the practice of genetics, including the fetus as a patient, pregnancy termination, confidentiality, and parents' right to know the risk of birth defects. Published quarterly.

Journal of Legal Medicine. American College of Legal Medicine, Inc., 801 North Rutledge Street, Suite 2149, P.O. Box 3926, Springfield, IL 62708.

Discusses various legal aspects of health care with many articles focusing on genetics and medical ethics.

Law, Medicine, and Health Care. The American Society of Law and Medicine, 765 Commonwealth Avenue, 16th floor, Boston, MA 02215.

Deals with the intersection of medical practice, law, and ethics. Many issues apply to a variety of medical specialties including genetics. Occasionally, articles deal specifically with reproductive and genetic concerns. Published bimonthly.

Medicine and Law: An International Journal. Springer-Verlag, Journal Production Department I, Postfach 105 280 D-6900, Heidelberg 1, Federal Republic of Germany.

Discusses current international legal thinking on medical issues. Topics with implications for the practice of genetics include euthanasia, abortion, malpractice, medical ethics, and medicine and religion. Published quarterly.

Reproductive Technologies

Books and Articles

Bai, K., Shirai, Y., & Ishii, M. (1987). In Japan, consensus has limits. *Hastings Center Report: Special Supplement, 17*(3), 18-20.

A discussion of *in vitro* fertilization, artificial insemination by donor and gender selection in Japan, and the ethics discussion provoked by these technologies.

Bermel, J. (1987). No rooms at the hospital for surrogate mothers? *Hastings Center Report, 17*(3), 2.

Reports on the debate over whether Catholic hospital officials should discourage the surrogate mother from choosing their institutions for delivery.

Bleich J. D. (1981). *Judaism and healing: Halakic perspectives.* New York: Ktav.

Includes chapters on genetic concerns such as host mothers, gender pre-selection, genetic screening, test tube babies, and abortion.

Boyd, K., Callaghan, B., & Shotter, E. (1986). *Life before birth: Consensus in medical ethics.* London: Holy Trinity Church.

A discussion of the views and statements of medical professionals, Parliament, and the Anglican and Catholic churches about artificial insemination, surrogacy, and abortion. Available from SPCK, Holy Trinity Church, Marylebone Road, London NW1 4DU.

Capron, A. M. (1984, October). The new reproductive possibilities: Seeking a moral basis for concerted action in a pluralistic society. *Law, Medicine and Health Care,* 192-198.

An overview of the ethics of reproductive technology, with a useful bibliography.

Carmen, I. H. (1985). *Cloning and the Constitution: An inquiry into governmental policy making and genetic experimentation.* Madison, WI: The University of Wisconsin Press.

Examines the constitutionality of legislation that might be used to regulate human genetic experimentation. One chapter (and its attendant appendices) presents the results of interviews with regulators, cloners, and campus biosafety committees. Includes bibliography (including court cases) and index.

Carney, T. P. (1981). *Instant evolution: We'd better get good at it.* South Bend, IN: University of Notre Dame Press.

Provides a critical evaluation of the ethics of reproductive and other technologies.

Eaton, T. A. (1985). Comparative responses to surrogate motherhood. *Nebraska Law Review, 65*(4), 686-727.

Surveys legislation covering surrogacy in the United States, Canada, the United Kingdom, and Australia; the ethics of surrogacy; and guidelines for resolving conflicts between the (biological) father and (biological) surrogate mother over pregnancy termination, prenatal care, and custody.

Fagout-Largeault, A. (1987). In France, debate and indecision. *Hastings Center Report: Special Supplement, 17*(3), 10-12.

Provides an overview of the politics and political economy of reproductive technology in France.

Gillon, R. (1987). In Britain, the debate after the Warnock Report. *Hastings Center Report: Special Supplement. 17*(3), 16-18.

A report on controversy in Britain over the Warnock Commission report on the ethics of human embryology experiments.

Mori, M. (1987). Italy: Pluralism takes root. *Hastings Center Report: Special Supplement, 17*(3), 34-36.

Surveys the Italian response to the Vatican proclamation on *in vitro* fertilization.

Ramsey, P. (1970). *Fabricated man: The ethics of genetic control.* New Haven, CT: Yale University Press.

Ramsey's classic book has served as the basis for much subsequent discussion in this field. He presents a carefully developed rationale for restricting a number of the new technologies such as artificial insemination and cloning.

Shapiro, A. (1987). In Israel, law, religious orthodoxy, and reproductive technologies. *Hastings Center Report: Special Supplement, 17*(3), 12-13.

Reports on the regulatory history of reproductive technology in Israel, and on the implications of this technology for the question of Jewish identity.

Singer, P., & Wells, D. (1985). *Making babies: The new science and ethics of conception.* New York: Charles Scribner's Sons.

Discusses the technical and ethical aspects of *in vitro* fertilization, surrogacy, and sex selection, and such still futuristic topics as cloning, ectogenesis, and genetic engineering. Appendices include statements and reports from Australia, the United Kingdom and the United States, and results of a survey of Australian couples who have undergone *in vitro* fertilization. Includes a bibliography and index.

Snyder, G. S. (1982). *Test-tube life: Scientific advance and moral dilemma.* New York: Simon & Schuster.

Covers recombinant DNA, *in vitro* fertilization, surrogacy, cloning, and the moral dilemmas posed by biotechnology.

Szawarski, Z. (1987). Poland: Biomedical ethics in a socialist state. *Hastings Center Report: Special Supplement., 17*(3), 27-29.

Reports on abortion and *in vitro* fertilization in Poland.

Waller, L (1987). In Australia the debate moves to embryo experimentation. *Hastings Center Report: Special Supplement 17*(3), 21-22.

Provides an overview of the legal climate for reproductive technology in Australia.

Walters, L. (1987). Ethics and new reproductive technologies: An international review of committee statements. *Hastings Center Report: Special Supplement, 17*(3), 3-9.

Surveys statements on reproductive technologies by bioethics committees in Australia, Great Britain, Canada, West Germany, Spain, France, the Netherlands, and the United States.

Warnock, M. (1986). Moral thinking and government policy: The Warnock committee on human embryology. *Health and Society, 63*(3), 504-522.

Warnock provides a summary of the report of the British committee of inquiry which she chaired. This landmark committee recommended more stringent regulation of artificial insemination by donor, the criminalization of the organizational promotion of surrogate motherhood; and licensing, regulation, and inspection of facilities that conduct research on human embryos.

Gene Therapy and Genetic Engineering

Books and Articles

Attanasio, J. B. (1986). The constitutionality of regulating human genetic engineering: Where procreative liberty and equal opportunity collide. *University of Chicago Law Review, 53*(4), 1274-1342.

A review of existing legislation and an attempt to apply the arguments of contemporary political philosophers in resolving conflicts arising from the distribution of genetically engineered superior talents.

Cavalieri, L. F. (1981). *The double-edged helix: Science in the real world.* New York: Columbia University Press.

A critical evaluation of recombinant DNA technology and its impact on society.

Church of the Brethren. (1987). *Annual conference statement on genetic engineering.* Washington, DC: Church of the Brethren.

A statement which raises many questions proposed for further study, and which offers some cautions, but which basically takes a permissive attitude to all non-military applications of genetic technology.

Fletcher, J. C. (1983). Moral problems and ethical issues in prospective human gene therapy. *Virginia Law Review, 69*(3), 515-546.

Extensive review of the controversies surrounding the possibility of the therapeutic alteration of DNA in both somatic cells and gametes.

Howard, T., & Rifkin, J. (1977). *Who should play God?* New York: Delacorte.

Rifkin is perhaps the best known exponent of the thesis that modern genetic practices, especially gene-splicing, are dangerously meddlesome and tantamount to playing God.

Moraczewski, A. S. (1983). *Genetic medicine and engineering: Ethical and social dimensions.* St. Louis: Catholic Health Association of the United States and the Pope John XXIII Medical-Moral Research and Education Center.

Presents the scope and limits of contemporary medical genetics, the interest in genetic engineering which these limits arouse, and the ethical and social concerns anticipated by these experimental new techniques for the lay person.

National Council of the Churches of Christ/USA. (1984). *Genetic engineering: Social and ethical consequences.* New York: Pilgrim.

Adopted from a study report of the Panel on Bioethical Concerns of the National Council of the Churches of Christ/USA, this book is useful as a resource for church study groups. Discussion questions and suggestions for group leaders are provided at the conclusion of each section.

National Council of Churches. (1980). *Human life and the new genetics: A report of a task force commissioned by the National Council of the Churches of Christ in the U.S.A.* New York: National Council of Churches.

An examination of genetic engineering with some theological answers and suggestions for involvement by the different denominations in the Council.

Office of Technology Assessment. (1984). *Human gene therapy: A background paper.* Washington, DC: Government Printing Office.

Provides a systematic examination of the types and techniques of gene therapy and their medical applications. It discusses the issues which could arise from clinical application, including parental responsibilities, trade secrets, social implications such as alteration of the gene pool, and the federal role in this new technology. Available from Government Printing Office, Superintendent of Documents, Washington, DC 20402. Ask for publication no. 052-003-00906-4.

Pines, M. (1987). *The new human genetics: How gene splicing helps researchers fight inherited disease.* Bethesda, MD: National Institute of General Medical Sciences.

Provides an examination at the lay level of current gene-splicing technology and the potential for gene therapy. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research. (1982). *Splicing life: A report on the social and ethical issues of genetic engineering with human beings.* Washington, DC: Government Printing Office.

This study carefully examines the social and ethical issues in light of the limitations and potential of current research.

Rifkin, J. (1983). Whom do we designate to play God? *Engage/Social Action, 11*(10), 22-28.

A summary of the 1977 book by Howard and Rifkin, *Who Should Play God?,* concerning modern genetic practices, especially gene splicing.

Seydel, F. D. (1982). Genetic manipulation. *The Christian Home, 14*(5), 19-21.

Examines the motivations for current genetic manipulations, and briefly looks at two major types, cloning and recombinant DNA.

Shannon, T. A. (1985). *What are they saying about genetic engineering?* Mahwah, NJ: Paulist.

Part of the *What are they saying about...?* series. Gives an overview of several contemporary developments in genetics and the ethical issues accompanying them.

Walters, L. (1986). The ethics of human gene therapy. *Nature, 20,* 225-227.

An overview of the techniques, prospective commerce, and research ethics of human gene therapy, especially single gene germ line therapy for inborn errors of metabolism.

Genetic Screening, Prenatal Diagnosis, and Fetal Therapy

Books and Articles

Ames, D. A., & Gracey, C. B. (Eds.). (1984). *Good genes? Emerging values for science, religion and society.* Cincinnati, OH: Forward Movement.

A group study guide on genetic screening, fetal therapy, and reproductive technology, written by officials of the Episcopal Church.

Bermel, J. (1987). To screen or not to screen for the fragile X syndrome. *Hastings Center Report, 17*(1), 2.

A report on the debate over whether to screen "intellectually handicapped" children to determine whether they have fragile X syndrome, and whether to offer screening to the families of those who are found to have this disorder.

Dougherty, C. J. (1985). The right to begin life with sound body and mind: Fetal patients and conflicts with their mothers. *University of Detroit Law Review, 63* (1 & 2), 89-117.

A discussion of the morality of providing needed fetal therapy against the will of the mother.

Faden, R., Chawalow, A. J., Quaid, K., Chase, G. A., Lopes, C., Leonard, C. O., & Holtzman, N. A. (1987). Prenatal screening and pregnant women's attitudes toward the abortion of defective fetuses. *American Journal of Public Health, 77*(3), 288-290.

A study of the attitudes of 490 pregnant women towards pregnancy termination due to abnormalities revealed through genetic screening. Three hundred of the women were participants in a prenatal screening program for neural tube defects.

Fletcher, J. C. (1983). Ethics and trends in applied human genetics. In S. C. Finley, W. H. Finley, & C. E. Flowers. (Eds.). *Birth defects: Clinical and ethical considerations. Birth Defects: Original Article Series, 19*(5), 143-158. New York: Alan R. Liss.

Examines the status of the major ethical debates accompanying prenatal diagnosis and fetal therapy.

Fletcher, J. C. (1979). Prenatal diagnosis, selective abortion, and the ethics of withholding treatment from the defective newborn. In *Genetic counseling: Facts, values, and norms. Birth Defects: Original Article Series, 15*(2), 239-254. New York: Alan R. Liss.

Specific ethical issues are discussed, as well as the history of genetic counseling and its applications.

Harsanyi, Z., & Hutton, R. (1981). *Genetic prophecy: Beyond the double helix.* New York: Rawson Associates.

A survey of the current and prospective means for identifying genetic markers for disease, longevity, IQ, depression, alcoholism, schizophrenia, etc. The potential uses and abuses of this information by employers, governments, medical professionals, insurers, and others is discussed.

Kowles, R. V. (1985). *Genetics, society and decisions.* Glenview, IL: Scott, Foresman.

Presents the basic concepts of genetics but also covers social controversies arising from genetic screening and engineering.

The new technologies of birth and death: Medical, legal and moral dimensions. (1980). Braintree, MA: Pope John Center.

Addresses genetic screening from the standpoint of Catholic moral theology.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). *Screening and counseling for genetic conditions: The ethical, social, and legal implications of genetic screening, counseling, and education programs.* Washington, DC: Government Printing Office.

Provides a comprehensive description of current screening services, including carrier, newborn, and prenatal screening, and of associated ethical concerns including confidentiality, autonomy, disclosure of knowledge, public and professional education, well-being, and equity. Uses cystic fibrosis as a case study for application of the various issues discussed.

Seydel, F. D. (1984). A collision of values in a "high-tech" age. *Engage/Social Action, 13*(4), 16-20.

Reflections on prenatal diagnosis and pregnancy termination.

Seydel, F. D. (1981). Genetic health. *The Christian Home, 14*(2), 34-35, 49-50.

Examines the unique aspects of genetic disease, including the dilemmas for patients and families.

Smurl, J., et al. (1984). Ethical considerations in medical genetics: The prenatal diagnosis of Hemophilia B. *American Journal of Human Genetics, 17*, 773-781.

The moral decisions faced by a family concerning further testing and treatment are examined in terms of perceived obligations and rights.

Steinbrook, R. (1986). In California, voluntary mass prenatal screening. *Hastings Center Report, 16*(5), 5-8.

A report on California's maternal serum alpha-fetoprotein screening program.

Walters, L. (1986). Ethical issues in intrauterine diagnosis and therapy. *Fetal Therapy, 1*, 32-37.

Discusses the implications of intrauterine diagnosis and therapy for decisions regarding pregnancy termination and the mother's right to refuse medical treatment beneficent for the fetus.

Critically Ill Newborns

Books and Articles

Bartholme, W. G., Martin, D., & Martin, R. (1986). *The imperiled infant: Law and clinical ethics.* Urbana, IL: Carle Medical Communications.

This volume, in the format of a looseleaf, spiral notebook, represents the results of a workshop offered in San Francisco, Washington, and Chicago, sponsored by the University of Illinois College of Medicine, Carle Medical Communications, and the Carle Foundation. Covers treatment of critically ill newborns, whether parents have the right to make decisions about the child-patient, the roles of family and doctor in decision making, criteria for withholding or withdrawing life-sustaining care, the American Academy of Pediatrics' guidelines for bioethics committees, the American Nurses' Association's code, ethical dilemmas, the legal and ethical issues about withholding treatment from the critically ill newborn, and judicial and administrative rulings and legislation. Includes a bibliography.

Guillemin, J. H., & Holmstrom, L. L. (1986). *Mixed blessings: Intensive care for newborns.* New York: Oxford University Press.

The authors cover the roles of professionals working in neonatal intensive care units, clinical decisions, and the family, and survey neonatal intensive care in the United States and abroad. Includes bibliography, glossary, and index.

Hammer, J. E., III, & Sax Jacobs, B. J. (Eds.). (1986). *Life and death issues.* Memphis: University of Tennessee.

This anthology covers ethical issues in neonatology, as well as other life and death issues.

Kimura, R. (1986). In Japan, parents participate but doctors decide. *Hastings Center Report, 16*(4), 22-23.

The author discusses the role of families and doctors in decisions about critically ill newborns in Japan.

Lynn, J. (Ed.). (1986). *By no extraordinary means: The choice to forego life-sustaining food and water.* Bloomington, IN: Indiana University Press.

Contains one contribution each on Jewish and Catholic perspectives on passive euthanasia. Several chapters discuss the Baby Doe case and the general issue of life-sustaining measures for infants born with life-threatening disorders.

Magnet, J. E., & Eike-Henner, W. K. (1985). *Withholding treatment from defective newborn children.* Cowansville, Québec: Brown Legal.

The author cover current Canadian practice, and legal and ethical aspects of treatment of critically ill neonates. Includes bibliography, table of cases, and index.

Chapter 2

Clergy Involvement in Genetic Counseling

Clinical Genetic Counseling

Books and Articles

Applebaum, E. G., & Fierstein, S. K. (Eds.). (1983). *A genetic counseling casebook.* New York: Macmillan.

An annotated collection of twenty-four varied genetic counseling cases provided by twenty-six professionals and one client. Provides insights into the work of the counselor and the different responses of patients to the counseling experience.

Baumiller, R. C. (1988). Genetic counseling. *NAMRP Quarterly Publication, 18,* 12-15.

Discusses why church related medical institutions have shied away from genetic counseling and genetic testing.

Biass-Ducroux, F., et al. (Eds.). (1970). *Glossary of genetics.* New York: Elsevier Science.

This volume is a multilanguage translation dictionary of genetic terminology. The first section is an alphabetized and numerically indexed list of almost 3,000 terms in English. Each term is followed by its equivalent in French, Spanish, Italian, German, and Russian, without definition. The remainder of the volume consists of alphabetized lists of terms segregated by language, each term followed by the index number for its equivalent in the English language section.

Capron, A. M., Lappé, M., Murray, R. F., Powledge, T. M., Twiss, S. B., & Bergsma, D. (Eds.). (1979). Genetic counseling: Facts, values, and norms. *Birth Defects: Original Article Series, 15*(2). New York: Alan R. Liss.

Discusses the history of genetic counseling, counseling as related to the concepts of genetic disease and health, the role of the counselor within the medical profession, professional qualifications, and ethics, including autonomy and confidentiality. Several specific ethical issues are also presented, including responsible parenthood, the relationship of prenatal diagnosis to selective abortion, and the withholding of treatment to critically ill newborns.

Clements, C. D. (1982). *Medical genetics casebook: A clinical introduction to medical ethics systems theory.* Clifton, NJ: Humana.

A synthesis of philosophy and medical case experience.

Comprehensive clinical genetic services centers : A national listing. (1985). Washington, DC: U.S. Department of Health & Human Services.

Lists comprehensive clinical genetic service centers and satellite clinics available in each state. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057.

Emery, A. E. H., & Pullen, I. (Eds.). (1984). *Psychological aspects of genetic counseling.* Orlando, FL: Academic.

Presentation of various components of genetic counseling. Emphasizes psychological impact of genetic disease upon the family.

Epstein, C. J., Curry, C., Packman, S., Sherman, S., & Hall, B. D. (Eds.). (1979). Risk, communication, and decision making in genetic counseling. *Birth Defects: Original Article Series, 15*(5c). New York: Alan R. Liss.

Topics discussed include anxiety, anger, the effect of genetic counseling on self-concept, non-verbal communication, parental response to uncertainty, a guide for amniocentesis decision making, and presentation and perception of risk.

Fraser, F. C., & Nora, J. J. (1986). *Genetics of man.* Philadelphia: Lea and Febiger

A comprehensive text on medical genetics which presupposes no background in the field.

Hsia, Y. E., Hirschhorn, K., Silverberg, R. L., & Godmilow, L. (Eds.). (1979). *Counseling in genetics.* New York: Alan R. Liss.

Provides a comprehensive view of genetic counseling. Also includes a chapter on basic human genetics.

International directory of genetic services. (1986). White Plains, NY: March of Dimes Birth Defects Foundation.

Provides a listing of genetic service providers in many countries.

Kelly, P. T. (1977). *Dealing with dilemma: A manual for genetic counselors.* New York: Springer-Verlag.

Integrates medical and genetic information with the psychosocial aspects of genetic counseling. Written in non-technical language and is primarily concerned with communication between counselor and counselee.

Kessler, S. (Ed.). (1979). *Genetic counseling: Psychological dimensions.* New York: Academic.

Examines the psychological factors present in persons with a high risk of, or who currently have, a serious genetic disease in themselves or their families. Attention to these factors enables counselors to communicate information more effectively and better help their patients deal with their concerns.

Kessler S., Kessler H., & Ward P. (1984). Psychological aspects of genetic counseling, III: Management of guilt and shame. *American Journal of Medical Genetics, 17*(3), 673-697.

The major counseling tactics alleviating or reducing feelings of guilt and shame are outlined and case illustrations are provided.

Lippman-Hand, A., & Fraser, F. C. (1979). Genetic counseling: Provision and reception of information. *American Journal of Medical Genetics, 3*(1), 113-127.

Transcripts of genetic counseling sessions were analyzed to determine communication difficulties concerning information on risk and consequences.

Riccardi, V. M., & Kurt, S. M. (1983). *Communication and counseling in health care.* Springfield, IL: Charles C. Thomas.

The two chapters on building supportive counseling relationships and on genetic counseling, which discuss the patient's needs and the means to remain open to the patient's point of view, are particularly helpful for pastors. Case studies included.

Temple, M. J. (1983). Preamniocentesis counseling. *Hospital Practice, 18*(6), 94E-94T.

The benefits of preamniocentesis counseling, regardless of whether pregnancy termination is contemplated, are examined.

Thompson, J. S., & Thompson, M. W. (1986). *Genetics in medicine.* Philadelphia: W.B. Saunders.

This text is written to introduce medical students to human genetics. It presupposes little or no background in genetics. Each chapter is referenced and many of the nineteen chapters have problems at the end. Answers to problems are provided in the back of the book. Glossary and index are included.

Journals and Periodicals

Genetics Digest. Foundation for Blood Research, P.O. Box 190, Scarborough, ME 04074.

A digest of recent literature in human genetics. Published monthly.

Genetics in Practice. March of Dimes Birth Defects Foundation, Professional Education Department, 1275 Mamaroneck Avenue, White Plains, NY 10605.

A brief update on major themes in clinical human genetics. Intended primarily for health professionals, the information presented is summarized adequately to be helpful to clergy. Published quarterly.

Pastoral Counseling About Genetics

Books and Articles

Atkinson, G., & Moraczewski, A. S. (Eds.). (1980). *Genetic counseling, the Church and the law.* Braintree, MA: Pope John Center.

This work is the result of an interdisciplinary Task Force on Genetic Diagnosis and Counseling assembled by the Pope John Center to examine the moral issues engendered by genetic counseling.

Baumiller, R. C. (1983). Clergy involvement: A dimension of real need. *Hospital Practice, 18*(4), 38A-38F.

Brief discussion of the opportunities open to clergy to work closely with families and individuals who are at risk for or affected with a genetic disorder.

Baumiller, R. C. (1981). *Genetic decision making and pastoral care: An invited conference.* White Plains, NY: March of Dimes Birth Defects Foundation.

Proceedings of a conference held at Georgetown University. The conference faculty explored the problems caused by the reproductive options given to individuals and couples by advances in medical genetics and medical technology and the need for faith groups to prepare their counselors and pastors to advise families competently.

Clark, M. W. (1981). The pastor as genetic counselor. *Journal of Religion and Health, 20*, 317-332.

Written by a pastor who became interested in genetics after the birth of his two children affected with a genetic condition. The article suggests pastoral roles on a genetics team.

Fletcher, J. C. (1983). Relating principle to practice. *Hospital Practice, 18*(4), 38F-38P.

A commentary on the expanding role of clergy in supporting persons with genetic disorders and their families.

Fletcher, J. C. (1982). *Coping with genetic disorders: A guide for clergy and parents.* San Francisco: Harper and Row.

A guide for clergy who must counsel couples who already have or are at risk of having a child affected with a genetic disorder. Many sections of the book are also informative for those interested in genetic counseling and in the dilemmas created by genetic technology.

Goodman, R. M. (Ed.). (1979). *Genetic disorders among the Jewish people.* Baltimore: Johns Hopkins Press.

A compendium of genetic disorders among Jewish groups including Ashkenazi, Oriental, and Sephardic Jews. Contains a section on common misconceptions about diseases which affect Jewish persons.

Goodman, R. M., & Motulsky, A. G. (Eds.). (1979). *Genetic diseases among Ashkenazi Jews.* New York: Raven Press.

Itemizes the diseases especially common among this ethnic group. Provides much technical detail on genetic patterns, clinical manifestations, and treatment.

Krieger, L. (1985, December 27). Clergymen counsel on genetic problems. *American Medical News*, 23.

A report on clergy involvement in counseling affected individuals and their families.

Lebacqz, K. (Ed.). (1983). *Genetics, ethics, and parenthood.* New York: The Pilgrim.

Developed as a workbook of exercises and reflections to be used as a resource in a congregational study group. The book has three sections: The Power to Be a Parent, Parenthood and the "Quality" of Children, and Making Decisions and Getting Involved.

Seydel, F. D. (1987). Ethical dilemmas in perinatal care: Opportunities for clergy assistance. In H. Travers, *Strategies in genetic counseling: I. Issues in perinatal care. Birth Defects Original Article Series, 23*(6), 16-24. White Plains, NY: March of Dimes Birth Defects Foundation.

Addresses the many ways that clergy can participate in resolving ethical conflicts for patients and professionals.

Seydel, F. D. (1981). Genetic counseling by pastors. *The Circuit Rider, 5*(10), 6-7.

A brief article in a United Methodist publication, intended to acquaint clergy with this new area of ministry.

Social and psychological aspects of genetic disorders: A selected bibliography. (1985). Washington, DC: National Center for Education in Maternal and Child Health.

Includes articles and books from professional literature and audiovisual materials produced by voluntary organizations and professional film makers. References cited are meant to assist health professionals to respond to the unique problems faced by individuals and families who are at risk for or have a genetic disorder. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057

Switzer, D. K. (1986). *The minister as crisis counselor.* Nashville: Abingdon.

Surveys psychological literature to provide insights for ministers in crisis counseling. Covers theory and methods of crisis counseling, intervention procedures, family crises, grief, pathological grief, divorce, suicide, and congregational and community services. Includes footnotes and index.

Weiss, F. L. (1984, April-May). Genetic counseling in a liberal Jewish context. *Reconstructionist*, 26-32.

Presents a permissive approach to contraception, sterilization, and abortion, and a much less permissive approach to euthanasia and the obligation to provide information about inherited disorders.

Weiss, F. L. (1984). *Jewish values in genetic counseling: A survey in methodology* (Rabbinical dissertation). Cincinnati, OH: Hebrew Union College—Jewish Institute of Religion.

Examines practical and religious counseling concerns from a Jewish perspective.

Journals and Periodicals

Journal of Pastoral Care. Journal of Pastoral Care Publications, Kutztown Publishing Company, P.O. Box 346, Kutztown, PA 19530.

Carries articles on counseling, decision-making, and coping with grief and mourning relevant to genetic illness and genetic counseling. Published quarterly.

Journal of Religion and Health. Human Sciences Press, Inc., 72 Fifth Avenue, New York, NY 10011.

Includes articles on topics relevant to genetic illness and genetic counseling. Published quarterly.

Chapter 3

The Religious Community and Persons with Disability

Books and Articles

Archdiocese of Boston. (1987). *Resource guide: Special religious education.* Boston: Archdiocese of Boston, Office of Religious Education.

An annotated bibliography of publications suitable for use in various religious educational services for the disabled.

Archdiocese of Chicago. (1985). *Access to the sacraments of initiation and reconciliation for developmentally disabled persons.* Chicago: Liturgy Training Publications.

Guidelines for instructing the disabled in the Catholic faith. Also available in Spanish as *Acceso a los Sacramentos de Iniciación y Reconciliación para Personas Inhabilitadas.* Available from Liturgy Training Publications, 1800 Hermitage Avenue, Chicago, IL 60622-1101.

Association for Retarded Citizens. (No date given.). *Congregational awareness program.* Arlington, TX: Association for Retarded Citizens.

Suggestions for a program to acquaint congregations with the presence of mentally retarded persons within their constituency or neighborhood areas and to help them see possibilities for expanding the congregation's programs to include mentally retarded persons and their families. Available from Association for Retarded Citizens, 2501 Avenue J, P.O. Box 6109, Arlington, TX 76011.

Bowers, F. (Ed.). (1985). *Let love be genuine: Mental handicap and the Church.* London: Baptist Union of Great Britain and Ireland.

Personal anecdotes from Baptists and Anglicans in the United Kingdom and Australia who are working with mentally disabled relatives and congregants. Available from Baptist Union, 4 Southampton Row, London WC1B 4AB.

Cook, E. (1986). *Sharing the journey: Active reflections on the Church's presence with the mentally retarded.* Dubuque, Iowa: William C. Brown.

Catholic clergy and lay people address the role of the Church, the medical profession, financial planning, special education, residential services, sexuality, and parent advocacy.

Coughlin, D. D., & Roby, L. (1982). *Welcome to my world: A simulation workshop designed to raise awareness of the needs and potential of persons with handicapping conditions.* Portland: Archdiocese of Portland.

A guide for the workshop director, including scripts for lectures and audiocasettes. Available from Special Pastoral Services, Archdiocese of Portland in Oregon, 8716 S.E. Ellis, Portland, OR 97266.

Developmental Disability Services. (1986). *Worship resources for disability awareness.* Elkhart, IN: Mennonite Central Committee.

Sermon ideas, bibliography, and a directory of Mennonite organizations working with persons with disabilities. Available from Developmental Disability Services, Box 370, 500 South Main, Elkhart, IN 46515.

Division for Parish Services. (No date given.). *Tips for congregations working with disabled persons.* Philadelphia: Lutheran Church in America.

This loose-leaf folder contains inserts on the moderately mentally retarded, those with hearing, speech, vision, and physical disabilities, the emotionally disturbed, and the autistic. Available from Division for Parish Services, Lutheran Church in America, 2900 Queen Lane, Philadelphia, PA 19129.

E.A.C.H. Lending Library Catalog Annandale, VA: Episcopal Awareness Center on Handicaps.

An extensive listing of resources for religious education and worship programs that include persons with disability. Available from E.A.C.H., 4805 Manion Street, Annandale, VA 22003

Education for Christian Life and Mission. (1986). *The wholeness of the family of God: Persons with disabilities.* New York: National Council of the Churches of Christ in the U.S.A.

A collection of position papers by Protestant and secular groups on persons with disabilities. Also contains worship materials, suggestions for group use, and a bibliography. Available from National Council of the Churches of Christ, Education for Christian Life and Mission, 475 Riverside Drive, New York, NY 10115.

Estes, D. T. (1984). *A humanizing ministry: A new direction for ministry with persons who are mentally retarded.* Scottdale, PA: Herald.

An exploration of the role of the minister, church, and wider community in ministering to the mentally retarded.

Heifetz, L. J. (1987). Integrating religious and secular perspectives in the design and delivery of disability services. *Mental Retardation, 25*(3), 127-131.

Discusses the issues of church accessibility, clergy as spokespersons and as advocates, existential questions arising from disabilities, clergy as service providers, and the need for an expansion of PL 94-142 to cover religious education for those who desire it.

Hogan, G. (Ed.). (1983). *The Church and disabled persons.* Springfield, IL: Templegate.

Discusses programs and services by churches to meet the needs of disabled persons for worship and education.

Kraus, G. (1981). *On hidden talents: A study of physical disabilities in relation to God's plan in Christ:* Minneapolis: Augsburg Publishing House.

This booklet contains sermon plans and mimeograph masters for teaching about the disabled.

Lutheran Christian Administration. (1981). *One body - one head - one mission: Suggestions for Christian ministries with disabled persons in the local congregation.* Philadelphia: Lutheran Christian Administration.

A booklet on ministering to the disabled, with an extensive bibliography of audiovisuals and print material, and a directory of organizations. Available from Division for Parish Services, Lutheran Church in America, 2900 Queen Lane, Philadelphia, PA 19129.

Malone, A. (1986). Spreading light: Religious education for special children. Mahwah, NJ: Paulist.

Reflects on the purpose of religious education, the special needs of the developmentally impaired, and the best methods for implementing a program that meets those needs. Includes suggestions on how to enlist support for a proposed education program, an annotated bibliography, and suggestions for three years of lesson plans.

Meulen, A. V. (1987). Grandma needs a cross too: The grieving process for a mentally retarded person. *NAMRP Quarterly Publication. 17*(4), 6-7, 25.

The author recounts the grieving process of her sister, who has Down syndrome, after the death of their grandmother.

Neufeldt, A.H. (Ed.). (No date given.). *Celebrating differences.* Winnipeg, Manitoba: Conference of Mennonites in Canada.

Theological, historical, and psychological essays, including coverage of the issues of religious instruction and family dynamics. Available from Mennonite Central Committee Canada, 134 Plaza Drive, Winnipeg, Manitoba R3T 5K9.

Noe, H. L. (1985). *A theology of ministry to the deaf.* Council Bluffs, Iowa: Deaf Missions.

Discusses ministry to the deaf as an example of cross-cultural ministry.

Paulhus, E. (1987). Personal space and relationships required for faith development: How a human being constructs personal time and space within the stages of development. *NAMRP Quarterly Publication, 17*(4), 12-15.

Discusses the importance of a sense of space and time in the development of human beings, especially persons with mental disabilities. Concludes that the socioaffective development of mentally retarded persons makes it possible to enlarge their sense of space by bringing them into the Christian community.

Paulhus, E. (1987). Relationship and Christian identity: Applying the principles of human development to the symbolic progression of a catechetical session. *NAMRP Quarterly Publication, 17*(4), 16-21.

Using the experience of preparation for the First Communion as an example, the author presents appropriate methods for presenting religious instruction to mentally retarded children. The emotions of the parents are also discussed.

Peachey, L. (1985). *Healing and hope.* Goshen, IN: Mennonite Disabilities Committee.

Suggestions for how a congregation can help the family with a disabled family member. Available from Mennonite Disabilities Committee, 1712 W. Clinton, Goshen, IN 46526.

Perske, R. (1980). *New life in the neighborhood: How persons with retardation or other disabilities can help make a good community better.* Nashville: Abingdon Press.

Discusses myths about the disabled.

Sumarah, J. (1987). L'Arche: Philosophy and ideology. *Mental Retardation., 25*(3): 165-169.

Discusses L'Arche communities (which integrate persons with and persons without mental disability), their disclosure of the value of persons with mental disability, their facilitation of mutual relationships, their provision of a sense of community, and their illumination of the spirituality of both those with and those without mental disability.

United Methodist Church. (1982). *Is our theology disabled? A symposium on theology and persons with handicapping conditions.* Cincinnati: United Methodist Church.

An anthology of reflections by and for lay people and clergy. Illustrated. Available from Service Center, 7820 Reading Road, Cincinnati, OH 45337.

Wagganer, K., & Standhart, R. T. (1987). Biblical attitudes toward the disabled. *NAMRP Quarterly Publication, 17*(4), 2-4.

The authors provide a resume of community standards regarding metaphoric and prophetic usages of, eschatological references to, and individual stories about disabilities from the Old and New Testaments.

Wilke, H. H. (1980). *Creating the caring congregation: Guidelines for ministering with the handicapped.* Nashville: Abingdon.

Discusses the role of churches in caring for the disabled. Reviews how the church has traditionally responded to the disabled. Includes a list of books, articles, audiovisuals, and agencies.

Wilke, H. H. (Ed.). (No date given.). *The open congregation: A handbook on accessibility, awareness, acceptance, advocacy with persons with disabilities.* White Plains, NY: The Healing Community.

A "clip and copy" handbook of sermons, visual teaching aids, and other materials, by a variety of Christian clergy and lay persons

Journals and Periodicals

Breakthrough. Bethesda Lutheran Home, 700 Hoffmann Drive, Watertown, WI 53904.

A newsletter that can be used in religious education for the mentally retarded. Published quarterly.

The Caring Congregation. The Healing Community, 139 Walworth Avenue, White Plains, NY 10606.

An interfaith newsletter for clergy and religious educators working with disabled persons. Published quarterly.

NAMRP Quarterly Publication and *National Apostolate with Mentally Retarded Persons Newsletter.* NAMRP Publication Office, 100 East Eighth Street, Cincinnati, OH 45202.

Publications available to members of the National Apostolate for Mentally Retarded Persons. Published quarterly and bimonthly.

Religion Division Newsletter. American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009.

Available to Association members only.

SPRED. Special Religious Education Division, Archdiocese of Chicago, 2956 South Lowe, Chicago. IL 60616. (312) 842-1039.

A newsletter for those involved in the religious education of persons with mental retardation. Published monthly.

Chapter 4
Support For Families

Coping with Grief

Books and Articles

Grollman, E. A. (1979). *How to explain death to children.* New York: Jewish Funeral Directors of America.

Discusses whether children should be shielded from death, whether children understand death, how one tells children about death, and whether children should attend the funeral and cemetery services. Though some of the material is specifically Jewish information, all is presented in a way that would be instructive to both Jews and non-Jews. Available from Jewish Funeral Directors of America, 122 East 42nd Street, Suite 1120, New York, NY 10168.

Hollingsworth, C. E., & Pasnau, R. O. (1977). *The family in mourning: A guide for health professionals.* New York: Grune and Stratton.

Discusses the various circumstances that can precipitate mourning including abortion, birth of a disabled child, death of a child, and death due to terminal illness. Ways of helping the family are provided, including the role of religion.

Kushner, H. V. (1981). *When bad things happen to good people.* New York: Schocken Books.

This rabbi's answer to the question of theodicy became a best seller. This question is frequently asked when a genetic or congenital defect is diagnosed.

Schiff, H. S. (1977). *The bereaved parent.* New York: Penguin.

Written for bereaved parents from the personal viewpoint of a mother who lost her ten-year-old son. Discusses the funeral, grief, and attitudes about religion.

Wass, H., & Corr, C. A. (Eds.). (1982). *Helping children cope with death: Guidelines and resources.* Washington, DC: Hemisphere.

Discusses children's attitudes about death and ways to counsel children who encounter death, whether it be the child's own impending death, that of a sibling, or that of a relative or friend. One chapter specifically discusses the role of the pastoral counselor. Its annotated bibliography of books for children and adults, and its comprehensive annotated list of audiovisual resources available for educating children about death make this book an exceptionally useful resource.

Journals and Periodicals

Caring Concepts. Centering Corporation, P.O. Box 3367, Omaha, NE 68103.

A newsletter by and for bereaved families.

Perinatal Bereavement

Books and Articles

Baumiller, R. C., Fletcher, J. C., & Madden, L. (in press). *A workbook for clergy to assist in pastoral care for individuals and families with special needs.* White Plains, NY: March of Dimes Birth Defects Foundation.

Includes prayers, services, and articles to assist clergy in providing pastoral care to those with special needs, including parents who have experienced a pregnancy loss.

Borg, S., & Lasker, J. (1981). *When pregnancy fails.* Boston: Beacon Press.

Discusses the grief experiences of parents caused by miscarriage, stillbirth, abortion or infant death, and discusses the role of the clergy and of support groups in helping bereaved parents cope. The appendices provide lists of national and regional support groups and of organizations and resources available for assistance.

Berezin, N. (1982). *After a loss in pregnancy: Help for families affected by a miscarriage, a stillbirth, or the loss of a newborn.* New York: Simon & Schuster.

Covers the responses in mourning of the couple, the community, the mother, caregivers, and siblings. Includes notes, bibliography, index, and a directory of local parent support groups.

Friedman, R., & Gradstein, B. (1982). *Surviving pregnancy loss.* Boston: Little, Brown.

Discusses types of pregnancy loss, the bereavement experience, and planning for future pregnancies. Includes bibliography, index, and a directory of parent support groups and adoption organizations.

A guide to resources in perinatal bereavement. (1988). Washington, DC: National Center for Education in Maternal and Child Health.

This guide was developed in collaboration with the National Perinatal Bereavement Alliance, and presents an annotated collection of information on perinatal loss, including materials on hospital programs, curricula, audiovisuals, and organizations. Available from the National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, DC 20057.

Hagley, N. D. (1985). *Comfort us, Lord: Our baby died.* Omaha: Centering Corporation.

Provides texts of prayers for bereaved family members.

Knapp, R. J., & Peppers, L. G. (1980). *Motherhood and mourning: Perinatal death.* New York: Praeger.

Discusses grief, tensions between husband and wife, the role of the physician, funeral arrangements and grave visits, subsequent pregnancy, and the need for support groups. Includes list of organizations and bibliography.

Lewis, E., & Page, A. (1978). Failure to mourn a stillbirth: An overlooked catastrophe. *British Journal of Medical Psychology, 1*, 237-241.

Early description in medical literature of the grief associated with pregnancy loss.

Panuthos, C., & Romeo, R. (1984). *Ended beginnings: Healing childbearing loss.* South Hadley, MA: Bergin & Garvey

Contains a chapter on spiritual needs of the grieving. Includes directory of support groups, bibliography, and index.

St. John's Hospital. (1986). *Starting your own SHARE group* (4th edition). Springfield, IL: St. John's Hospital.

A manual and directory of resources for those planning to organize a parent support group for the bereaved. Available from St. John's Hospital, 800 East Carpenter Street, Springfield, Il 62769.

Vredevelt, P. W. (1984). *Empty arms: Emotional support for those who have suffered miscarriage or stillbirth.* Portland: Multinomah.

Discusses grief, anger, the feelings of husbands and siblings, postpartum nutrition and exercise, mood swings, and subsequent pregnancies. Two chapters discuss spiritual themes.

Journals and Periodicals

SHARE Newsletter. St. John's Hospital, 800 East Carpenter Street, Springfield, IL 62769.

A newsletter by and for lay people and clergy dealing with bereavement. Published bimonthly.

Coping with Disability within Families

Books and Articles

Dickman, I., & Gordon, S. (1985). *One miracle at a time: A guide for parents of disabled children.* New York: Simon & Schuster.

Covers having a child diagnosed, finding other parents with disabled children, learning about the disability, genetic counseling and abortion, choosing doctors and therapists, institutionalization, early intervention, financial aid, special education, advocacy, life after high school, and sexuality. Includes bibliography and list of organizations.

Elkins, T. E., Anderson, G. D., & Spinnato, J. A. (1985). Helping parents adjust to Down's syndrome. *Contemporary Ob / Gyn, 25*(3), 56-64.

Three physicians discuss helping parents of children with Down syndrome deal with anger, denial, guilt, and sorrow.

Fairfield B. (1983). Parents coping with genetically handicapped children: Use of early recollections. *Exceptional Children, 49*(5), 411-414.

Discusses technique of obtaining parents' early memories of their child's disabling condition to uncover the true feeling of parents, identify critical concerns, and predict future difficulties for the families.

Featherstone, H. (1980). *A difference in the family: Life with a disabled child.* New York: Basic Books.

A detailed examination of the emotions and interactions of family members in response to the birth and development of a seriously disabled child.

Lester, A. D. (Ed.). (1987). *When children suffer: A sourcebook for ministry with children in crisis.* Philadelphia: The Westminster Press.

Lester has collected articles by pastors, therapists, community mental health workers, and professors of psychiatry and of child education. Articles cover children's needs for religious instruction and support from adults during divorce of parents, bereavement, hospitalization, and terminal or chronic illness, after abuse, or when possessed of disabilities, stress, or anxiety.

McDonald-Wikler, L. (1986). *Stresses and strengths of families of children with mental retardation.* Washington, DC: Joseph P. Kennedy, Jr. Foundation. Washington, DC.

Discusses the problems (impoverishment, marital stress, social isolation) of parents of a child with mental retardation, and the resources (socioeconomic status; religious belief; supportive, especially rural or religious, communities) that help families deal with these problems. In her opening remark the author expresses her belief that parents of the child with mental retardation often turn to the clergy before seeking other professional services. Available from The Joseph P. Kennedy, Jr Foundation, 1350 New York Avenue, N.W., Suite 500, Washington, DC 20005-4709.

Miezio, P. M. (1983). *Parenting children with disabilities: A professional source for physicians and guide for parents.* New York: Marcel Dekker.

Examines, according to the developmental sequence, problems parents of disabled children will encounter. Later chapters discuss strategies for obtaining assistance, including financial assistance, from agencies within the community.

Milunsky, A. (Ed.). (1981). *Coping with crisis and handicap.* New York: Plenum.

Proceedings from a national symposium. Extensive discussion of concerns in, and strategies for, dealing with illness and death of children by parents and siblings, and by the family's helping professionals, including nurses, teachers, and clergy.

Riesz, E. D. (1984). *First years of a Down syndrome child.* Iowa City, IA: University of Iowa Publications.

Chronicles the experiences of one family's coping with the unexpected birth of a Down syndrome child. Though different Down syndrome children will vary, and family conditions will also vary, the realistic presentation of problems and negative emotions and reactions by family, friends, and community provide reassurance and help define reasonable expectations for other parents with a disabled child.

Sickle cell: A selected resource bibliography. (1985). Washington, DC: National Center for Education in Maternal and Child Health.

Lists a wide variety of resources including books, pamphlets, films, slides, and audio- and videocassettes. Materials range from simple to very technical. Available from National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057.

Weiss, J. O., Bernhardt, B. A., & Paul, N. W. (Eds.). (1984). Genetic disorders and birth defects in families and societies: Toward interdisciplinary understanding. *Birth Defects: Original Article Series 20*(4). White Plains, NY: March of Dimes Birth Defects Foundation.

Exploration of a multitude of ethical, religious, legal, and counseling concerns by geneticists, genetic counselors, clergy, social workers, lawyers, educators, and parents.

Wikler, L., & Keenan, M. P. (Eds.). (1983). *Developmental disabilities: No longer a private tragedy.* Silver Spring, MD: National Association of Social Workers and American Association on Mental Retardation.

Provides information about the importance of social work services for the disabled, their families, and communities.

Journals and Periodicals

Especially Grandparents. King County Association for Retarded Citizens. 2230 Eighth Avenue, Seattle, WA 98121.

A newsletter for the grandparents of children with disabilities. Published quarterly.

Support Groups

Books and Articles

Madara, E. J., & Peterson, B. A. (1987). Clergy and self-help groups: Practical and promising relationships. *The Journal of Pastoral Care, 41*(3), 213-220.

Traces the genesis of self-help groups from religious institutions, and the continued interrelations of the two groups, and then codifies five roles for the clergy: referrals, developing local groups, providing meeting space, motivating religious institutions to develop groups, and developing support groups that serve clergy. Includes a directory of self-help groups.

Weiss, J. O., Karkalits, J. E., Bishop, K. K., & Paul, N. W. (Eds.). (1986). Genetic support groups: Volunteers and professionals as partners. *Birth Defects Original Article Series, 22*(2). White Plains, NY: March of Dimes Birth Defects Foundation.

Written by genetics service providers, organizers of voluntary groups, and parents. Designed to help established organizations as well as new support groups.

Directories

A guide to selected national genetic voluntary organizations. (1988). Washington, DC: National Center for Education in Maternal and Child Health.

Lists over 150 support groups and voluntary organizations for genetic disorders. Gives a statement of purpose for each organization and lists available educational materials. Available from the National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, DC 20057.

Office of Special Learning Needs. (1987). *Persons with special learning needs: Resources.* New York: National Council of Churches of Christ in the U.S.A.

A bibliography and directory of organizations covering autism; cerebral palsy; epilepsy; mental retardation; hearing impairments; learning disabilities; mental and emotional illnesses; physical, social, and visual disabilities; and the gifted and talented. Available from the National Council of Churches of Christ, Education for Christian Life and Mission, 475 Riverside Drive, New York, NY 10115.

Parent resource directory: For parents and professionals caring for children with chronic illness or disabilities. (1987). Washington, DC: Association for the Care of Children's Health.

A directory of local, parent-run, self-help and support groups for persons and families of persons with chronic disabilities. Organized by state, indexed by disorder, and by name of parent. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057.

Reaching out: A directory of voluntary and professional organizations in maternal and child health. (1988). Washington, DC: National Center for Education in Maternal and Child Health.

Provides a comprehensive reference to organizations with maternal and child health interests. Includes support groups for families, self-help clearinghouses, and professional organizations. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057.

Resource guide to organizations concerned with developmental handicaps. (1988). Silver Spring, MD: American Association of University Affiliated Programs.

A directory of university affiliated programs; state, regional, and Federal maternal and child health agencies; and advocacy groups.